

**Iowa Autism Council Meeting Draft Minutes**  
**November 13, 2013**  
**Meeting minutes taken by Beth Buehler-Sapp**

**Present:** James Curry, Linda Wessels, Jim Mumford, Laura Larkin, Steve Johnson, Jan Turbes, Alyson Beytien, Matt O'Brien, Theresa Croonquist, Andrew Waldschmitt, Barb Khal, Sean Casey and Beth Buehler-Sapp.

**Absent:** Steve Muller, Josh Cobbs, Rachel Heiss, Kathy Levine, Robin Sampson, Becky Harker and Deb Waldron.

Meeting was called to order and meeting participants when around the room and gave brief introductions of themselves.

James went over the 2011 Priorities submitted to the Legislature and Governor's Office as listed below:

**LEGISLATIVE PRIORITIES**

1. Require Department of Human Services (DHS) to amend the Intellectual Disabilities waiver to add Autism Spectrum Disorders (ASD) as an eligible group and determine eligibility through an individual clinical assessment that is based upon need and functional impairment criteria.

In relation to priority #1 with regard to the IME waiver process the intent is to amend the Intellectual Disabilities waiver. Alyson Beytien talked about mental health redesign meeting discussion whose intent was that for individuals with Autism IQ scores would not exclude them from eligibility for services if the assessment process determined that they lacked certain abilities while IQ score may have tended to make evaluator s think otherwise.

Matt O'Brien mentioned that the new DSM5 code has a silver lining in that it doesn't just look at scoring but that persons without significant adaptive behavior may now qualify for services whereas previously they would not have.

Alyson was able to recently move him son Zach back to in-state placement after 6 years in out of state placement. This was due to a new program called Hills and Dales in Dubuque, Iowa and run by Marilyn Althoff. This program rather than using exclusively a diagnosis or IQ score bases its decision for placement on assessments determining the individual's cognitive abilities.

Barb Khal mentioned that Deb Waldron is on the Children's Disability Workgroup and that perhaps she might have input for the council. Alyson Beytien asked if we could we can get an update from Deb when possible. Laura Larkin said that the report from the Children's Disability Workgroup will be available to the public on November 15<sup>th</sup>, 2013 (In 2 days).

2. Required to amend the Intellectual Disabilities and Ill and Handicap Waivers to allow behavioral treatments such as Applied Behavior Analysis to be covered treatments.

There was discussion regarding ABA Treatments and whether there was been any changes in how this gets regulated/accepted. The council's recommendation was to accept behavioral treatments such as ABA.

Two problems discussed regarding this are;

1. Current standards don't recognize ABA treatments being provided by staff persons working under the direction of a BCBA rather than each person providing treatments having to have an individual BCBA certification.
2. Some providers are coding their services under SCL (Supported Community Living) and are these actually ABA treatments labeled as SCL services.

James Curry suggested waiting on the Children's Disability Workgroup's recommendations with regard to this before pursuing this topic further.

3. Replace the dollar cap on county property tax levies with a levy rate cap and allow counties flexibility in determining which base year to use as the capitation rate. We believe that if this legislation was introduced as a "stand alone" bill it would have bi-partisan support and support from counties.

This priority was discussed generally but Steve Muller who was not at this meeting is considered to be the council member most knowledgeable about this priority. There was discussion that indicated that the Heaton Autism Fund may help some individuals who are ineligible for needed services due to this restriction.

4. Increase choice for Iowans with autism to live in their community through the expansion of Home and Community Based Services (HCBS) certified homes and Intermediate Care Facilities-Mental Retardation (ICF-MR) licensed homes of 4 persons or less.

The Hills and Dales program in Dubuque is a start to getting HCBS qualified units which allow Individuals with Autism to reside in their own communities. However, it's one small step for a small number of individuals residing in this part of the state. Hopefully, more such programs and residences will develop geographically to provide more choices for individuals with Autism. According to Alyson Beytien for the four young men living in the unit, they have for the month of October been able to decrease their behavior episodes by 50%. This is a large improvement.

Also due to a law change facilities previously called ICF-MR are now title ICF-ID. This is a positive change that has been made due to the reform movement towards persons with Intellectual Disabilities. Sean Casey points out that there are programs out there where the limited availability may be due to a funding issue.

The group as a whole expressed Transition, Education, & Employment are our major continued focus areas.

5. Amend the Hawkeye Healthcare plan to ensure that behavioral treatments such as Applied Behavior Analysis are covered treatments.

If individuals need services not covered under Hawkeye Healthcare then we hope for them to be able to access the Heaton Autism Fund or other such resources to cover this deficit that is available due to their Hawkeye Healthcare coverage.

Lin Wessels wonders whether the Affordable Healthcare Act has affected special populations such as the ASD population? The group was in consensus that it's too early to tell that at this time.

6. Expand the coverage that was passed for state employees last year for ASD treatments to all insurance plans regulated by state insurance rules.

Laura Larkin reported that Representative Heaton was told by the legislature that no insurance mandates will be entertained this legislative session. Jim Mumford told the group that even though the Iowa Insurance Commissioner last month sent a letter of recommendation to the legislature that they still have the ability to accept or deny recommendations.

7. Require 100 percent of the area education agencies (AEAs) to offer sibling training for siblings of people with ASD by Fall 2011.

Priority #7 was discussed and the consensus was that this is not really a recommendation for the legislature but more realistically a recommendation to go to the AEA's through the Department of Education. Sean mentioned that this can be communicated to the AEA's through the monthly DE meeting with all of the Special Education Directors from the AEA's.

There was general discussion about the pros and cons of sending an introductory letter within the report that goes to the legislature and the Governor's office. James stated that the council would not want the letter to obscure the report or the report to obscure the letter. More consideration will be given to this before the actual submission of the report in December.

James Curry distributed copies of a letter that went to Director Charles Palmer of the Iowa Department of Human Services and Director Rodney Roberts of the Iowa department of Inspections & Appeals. This letter was from a James Paprocki of Boone Iowa and was dated August 22, 2013. The letter also has co-signers of Kris Steimetz, Executive Director of the Autism Society of Iowa and Mazie Johnson, Executive Director of the Arc of Iowa. The main body of the letter is as follows:

The Iowa Code provides for emergency discharge from an intermediate care facility 481 64.36(1)(c)(I). However, the law does not delineate procedures that take into consideration the best interests of the person being discharged.

I am writing to ask for your assistance in making a policy change in the next legislative session. There currently is a practice in which provider agencies transfer a person with an autism spectrum disorder or intellectual disability from an ICF-ID to a Mental Health Unit. The person subsequently is discharged from the ICF-ID facility and no longer receives these services. I am advocating for legislation to place a moratorium on this practice. In effect, the person has been committed to the Mental Health Unit and has no permanent placement.

There are at least 5 reasons why a moratorium is needed:

An autism spectrum disorder or intellectual disability is a developmental disability and **not** a mental illness.

The use of mental health hospitalization as a temporary placement is an inhumane practice for persons with an autism spectrum disorder or an intellectual disability.

There is no **hearing** to determine whether mental health hospitalization is appropriate for a person with an autism spectrum disorder or an intellectual disability.

The practice of mental health hospitalization is punitive rather than supportive. It is inconsistent with the concept of least restrictive placement.

The staff in a Mental Health Unit lacks the appropriate knowledge or training to work constructively with a person with an autism spectrum disorder or an intellectual disability.

Let me further suggest the Iowa Department of Human Services establish an Autism Workgroup. This workgroup would be able to make policy recommendations based on the unique needs of persons with an autism spectrum disorder. An Autism Workgroup would be consistent with the recommendations of workgroups as part of Mental Health and Disability Services Redesign. It is imperative that Iowa provide supportive community-based services for persons with an autism spectrum disorder. The paradigm should include respect, dignity, and support from professionals who have knowledge and an appropriate understanding of autism spectrum disorders.

After reviewing Mr. Paprocki's letter and discussing his personal story which was the subject on extensive newspaper coverage last year the council collectively to invite Mr. Paprocki to speak at their next regularly scheduled meeting in January of 2013.

Alyson Beytien commented in relation to this story "The expenditure becomes really high when the only way we are addressing it is at Crisis Mode." This story illustrates the financial and life struggles that arise.

James Curry suggested that the council will consider the idea of developing a workgroup to look at addressing issues like those in Mr. Paprocki's letter.

Sarah Brown, Bureau Chief and Barb Guy, Director of Special Education just returned from a visit to the Marcus Autism Center in Atlanta. There is a plan to meet with Sean Casey, Autism Consultant about their visit and how this might impact our goals in Iowa.

The group talked about the staffing ratios that are typical in most residential facilities. Typically, this is 50% permanent employees and 50% transient employees. The hope is that if we can mandate a higher pay scale for folks working in these facilities that this would improve the ratios to have a much higher percentage of permanent employees. This would save money in retraining costs and have more continuity for facilities.

The council also discussed the Heaton Autism Fund and that the window for use of these funds goes from January 1, 2013 through June 30, 2013. The group will discuss this further and possibly decide at the January meeting to submit a request for an extension of the window of time through which these funds are available.

Barb Khal mentioned to the group that in conjunction with the Children's Disability Work Group that the CHSC (Child Health Specialty Clinics) has 13 regional CHSC offices and that they are working on efforts to organize resources in their areas. They hope this will benefit more patients on a statewide spectrum.

Andrew Waldschmitt commented that from a client's perspective it's important to keep supports in place after a person finishes schooling because there are still so many day to day living challenges which they need to achieve.

Within the council 3 members volunteered to participate in a workgroup (James, Linda, & Andrew) and spend the next week looking at a website at the following link and then reporting back to the group about the pros and cons of this website. [http://www.ucp.org/the-case-for-inclusion/2013/state\\_scorecards.html](http://www.ucp.org/the-case-for-inclusion/2013/state_scorecards.html)

Alyson Beytien – Why does Iowa not use Core Indicators?

James mentioned that there is a special meeting on the calendar for convening on December 11th to finish work on the 2014 Report to the Legislature and Governor's office if we don't get our work finished by then and need to meet on this date.

A question was asked by the council as a whole, "Are Iowa universities pumping out folks that can address students with Autism?"

Sean Casey stated, "The Iowa Department of Education is heavily invested in RtI (Response To Intervention) at this time and that this may provide some traction for this group.

Sean updated the council on his work with regard to BCBA programs within the state. Sean has one university currently implementing a BCBA education program and is working with two others and hoping to get programs implemented at those two universities as well.

Steve Johnson volunteered to look at the Standardization of Codes issue and work on this and report back to the council at the meeting in January 2014.

At 3pm James Curry made a motion to adjourn the meeting and Linda Wessels seconded the motion.